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## Greetings!

I have had the pleasure of talking with many people with developmental disabilities and family members. It is clear from these conversations with stakeholders that people often experience confusion and frustration when working with multiple systems and processes to get their needs met. "Navigating the System" was developed to provide information in a clear way as an aid in understanding how the various systems and processes work and where further information can be obtained.

This guidebook was developed through the efforts of the people noted on the facing page, many of whom are self advocates and family members. While it does not answer every possible question, this book should help in finding answers to most questions.

Staff from the Division of Developmental Disabilities (Division) review this guide periodically and update it as needed. All updates are posted on the Division's web site at <a href="https://www.azdes.gov/ddd">www.azdes.gov/ddd</a>. If you do not have access to the Internet at home or through your local library, you may call your Support Coordinator to obtain an updated copy. If you have suggestions to improve future editions of the guidebook, I encourage you to share them with us at 602.542.6823 or 866.229.5553 (toll free).

It is my hope that "Navigating the System" proves useful and a source of valuable information.

Cordially,

Barbara Brent, Assistant Director,
Department of Economic Security

Division of Developmental Disabilities

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# OVERVIEW OF THE DIVISION OF DEVELOPMENTAL DISABILITIES

## Why did you give me this guidebook?

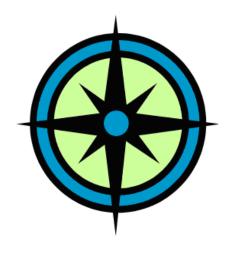
Life is complicated. Systems supporting people with developmental disabilities are even more complex. This guidebook is intended to help understand the many systems that may be encountered as a self advocate or someone involved in the life of a individual with a developmental disability. Some of the information contained in this guidebook may never be needed, but think of it as a car manual: When something happens, easy access to information is required. This guidebook provides necessary information to help "Navigate the System".

## What is the Division of Developmental Disabilities?

The Division of Developmental Disabilities (Division) is the state agency that provides supports and services for eligible people who have autism, cerebral palsy, epilepsy or a cognitive disability or children under the age of six that are at risk of having a developmental disability.

The term 'cognitive disability' replaces the term 'mental retardation' pursuant to recent changes in Arizona Revised Statute.

Additional information about the Division may be found in Chapter 200 of the Policy and Procedures Manual. The manual can be read at a local Division office or through the DDD website at http://www.azdes.gov/ddd/reference/policyproc.asp.



#### **MISSION**

To support the choices of individuals with disabilities and their families by promoting and providing within communities, flexible, quality, individual-driven supports and services.

#### VISION

Individuals with developmental disabilities are valued members of their communities and are involved and participating based on their own choices.

#### **VALUES**

#### We Value:

- Healthy relationships with people;
- Individual and family priorities and choices;
- Equal access to quality supports and services for all individuals and families;
- Partnerships and ongoing communication with individuals, family members, advocates, providers, and community members;
- Developmental approaches changing conditions that affect people rather than changing people who are affected by conditions;
- Individual freedom from abuse, neglect and exploitation with a balance between the right to make choices and experience life and individual safety;
- A diverse workforce that is motivated, skilled and knowledgeable of the most effective practices and utilizes them;
- An environment rich in diversity in which each individual is respected and has the opportunity to reach their optimal potential;
- An individual's right to choose to participate in and contribute to all aspects of home and community life;
- A system of supports and services which is:
  - Responsive timely and flexible responses to internal and external customers;
  - Strength based recognizing people's strengths, promoting self-reliance, enhancing confidence and building on community assets;
  - Effective ongoing identification of effective methods and practices and incorporation of those practices into operations; and
  - Accountable to our customers and to taxpayers.

## **ELIGIBILITY**

## Who is eligible?

To qualify for Division supports and services an individual must:

- a) Voluntarily apply;
- b) Be an Arizona resident;
- c) Have been diagnosed with autism, cerebral palsy, epilepsy or a cognitive disability which was manifest before the age of 18 and is likely to continue indefinitely; and
- d) Have substantial limitations in at least three or more of the following life functions:
  - Self-care:Eating, hygiene, bathing, etc.
  - Receptive and expressive language: Communicating with others;
  - Learning: Acquiring and processing new information;
  - Mobility: Moving from place to place;
  - Self-direction: Managing personal finances, protecting self-interest, or making independent decisions which may affect well-being;
  - Capacity for independent living: Needing supervision or assistance on a daily basis;
  - Economic self-sufficiency: Being financially independent.

Infants and toddlers under the age of six years may be eligible for services if they exhibit a significant delay in one or more areas of development. If under age three (3) a child may be eligible if determined to be at risk of having a developmental disability if supports and services are not provided.

#### Who determines eligibility for services through the Division?

Specially trained Intake staff of the Division will make the determination. If eligibility is questionable, a committee will review the documentation.

# Once I'm found eligible, am I always eligible?

No. Even though at one time the Division's eligibility criteria may be fully met, effective supports and services may later increase abilities so supports and services are no longer needed. That is why eligibility is re-determined at two set times in an individual's life.

#### When does it happen?

Eligibility will be re-determined before the age of six years and again before the 18th birthday. A re-determination may also take place at any time if evaluations indicate that support and services may no longer be needed.

#### What do I need to do?

Always get and keep copies of all evaluations, service progress notes, medical records, etc. Have these available for the Intake Staff.

## Where can I get more information about eligibility?

Additional information about eligibility can be found in Chapter 500 of the Policy and Procedures Manual. The manual can be read at a local Division office or through the DDD website.

#### **ELIGIBILITY FOR LONG TERM CARE**

#### What are the criteria?

A person may not have more than \$2,000 in cash or assets and income may not exceed 300% of the Federal Benefit Rate, e.g. Supplemental Security Income. Parental income may be waived for a child under the age of 18. The Arizona Health Care Cost Containment System (AHCCCS) makes this determination.

A person must have medical and functional needs and therefore be "at risk of institutionalization". A pre-admission screening by AHCCCS will determine medical and functional status.

## Who determines eligibility for Long Term Care?

AHCCCS determines Long Term Care eligibility.

## How often will Long Term Care eligibility be reassessed?

Ask the AHCCCS staff making the Long Term Care eligibility determination when reassessment will be made; it may vary based on a variety of factors.

#### What do I need to do?

Complete a financial information form and provide answers to AHCCCS staff conducting the pre-admission screening. Copies of any evaluations or other records may be required.

Cooperation with Long Term Care eligibility determination is required to receive any services funded through the Division.

## SUPPORT COORDINATION

## What is the role of a Support Coordinator?

The primary role of a Support Coordinator is to listen to the desires and needs of a person and family in a non-judgmental manner and ensure these desires and needs are respected and included in a person's plan as appropriate. A Support Coordinator may play a variety of roles depending on the needs of the individual and family.

The role of a Support Coordinator may include:

- Facilitator a Support Coordinator may facilitate the team that develops and implements an Individual Support Plan.
- Advocate a Support Coordinator may advocate for the needs of the person as identified by an individual and family.
- Teacher/Modeler a Support Coordinator may help a person gain self-advocacy skills.
- Coordinator a Support Coordinator may coordinate or assist in the coordination of supports and services.
- Mediator a Support Coordinator may facilitate effective communication between a person and family and other systems with a focus on collaboration.
- *Information Source* –a Support Coordinator has knowledge of community supports, other systems, supports from the Division, etc.
- Monitor a Support Coordinator will monitor the plan to ensure appropriate implementation of the supports and services, progress toward goals and quality of supports and services.



#### TARGETED SUPPORT COORDINATION

#### What is it?

Targeted Support Coordination allows an individual/responsible person to determine the frequency and type of contact desired from the Support Coordinator. This program does not provide for other services covered by Long Term Care such as respite, habilitation, etc.

## Who is eligible?

A person who is eligible for Medicaid but not eligible for Long Term Care is eligible for Targeted Support Coordination.

## How do I get it?

A person eligible for Targeted Support Coordination will be contacted by a Support Coordinator to discuss support needs.

## PLANNING FOR SUPPORTS AND SERVICES

## What are all these different plans?

The Division is responsible for developing and implementing a plan for services. The plan may be called an "Individual Support Plan" or a "Person Centered Plan". For a child who is in school, the school will develop an "Individualized Education Program" or for a very young child, the plan will be called an "Individualized Family Service Plan". Regardless of what it is called, a plan is needed to ensure appropriate supports and services are provided to an individual and to detail how they will be monitored.

## Why is planning important?

Planning is important because it creates a guide that defines supports and services that will help a person in reaching goals.

#### How does it work?

The team meets and reviews an individual's strengths, resources and capabilities as well as areas where assistance may be needed. The written plan details long-term goals, objectives and outcomes as well as the supports and services to be provided. The plan also helps measure a person's progress toward goals. The plan is flexible and may change as needed.

## Who participates?

The team consists, minimally, of the person and a Support Coordinator. Other team members may be family members, therapists or other providers. The person or the family determines the team membership. Often, the person or their families invite other family or friends, or even an advocate to be a team member/planning participant.

## How often does it happen?

The plan must be reviewed at least annually and more often if circumstances change.

## What does a plan look like?

The plan is a written statement, developed by the team, identifying the goals and outcomes for the person and the needed supports and services to be provided.

## Can I have a copy?

All team members will get a copy of the plan.

#### Where can I find more information?

Additional information about plans may be found in Chapter 800 of the Policy and Procedures Manual. The manual can be read at a local Division office or through the DDD website.

#### **SERVICES**

#### What services are available?

The following services may be provided based on assessed need as outlined in the "Planning for Supports and Services" section of this guidebook and depending on available funding and eligibility:

Attendant Care: This service provides a certified and trained attendant to assist an individual in attaining or maintaining safe and sanitary living conditions and/or maintaining personal cleanliness and activities of daily living. In providing this service the attendant might help the individual to get ready to start the day by assisting with bathing and dressing or by helping to complete housekeeping chores to assist in keeping a clean home.

<u>Day Treatment and Training:</u> This service provides training, supervision, therapeutic activities, and counseling as appropriate to promote skill development in independent living, self-care, communication and social relationships. This service is typically offered in a day program setting and activities might include learning to budget or prepare a meal.

<u>Employment Supports and Services:</u> These services provide people with the assistance needed to maintain gainful and productive employment. There are five funded employment services:

- *Individual Supported Employment* This service provides regular contacts at a person's job site in the community;
- Group Supported Employment This service provides supervision to small groups
  of people working in a community setting;
- Center Based Employment This service provides supervised employment within a provider owned/leased facility where the majority of the workers are people with disabilities;
- Employment Support Aide This service provides people with the one-toone support needed in order for the person to remain in employment; and
- Employment Related Transportation This service provides people with transportation to and from an employment location.

<u>Habilitation</u>: This service uses a variety of methods designed to maximize a person's abilities. This service is typically offered in a person's home and might include activities to help the person learn to brush their teeth, to become independent in using the bathroom, to cook a meal or balance a check book. The services provided are specific to a person's needs in learning to become more independent in certain areas.

<u>Home Health Aide</u>: This service is provided in a person's home and provides medically necessary health maintenance, continued treatment or monitoring of a health condition. This may include assistance with activities of daily living. A Home Health Aide serves as an assistant to the primary caregiver, under the supervision of a registered nurse. The Aide will follow a plan of care based upon an person's medical condition as prescribed by a Primary Care Physician.

Home Modifications: Under certain circumstances, Long Term Care eligible people may receive certain home modifications. These modifications will remove barriers in a person's home and will assist in making living as independent as possible. This service covers only modifications to existing structures and does not cover adding on to the home. Modifications can be made to individual/family owned homes where the person resides. If the home is rented, the owner must give written consent to modify the home. Landlords may not refuse to permit, at the expense of the person, reasonable modifications of existing premises occupied or to be occupied by a person if the modifications may be necessary to afford that person full enjoyment of the premises. Where it is reasonable to do so, a landlord may require that the renter restore the premises to the condition that existed prior to the modification.

<u>Home Nursing</u>: This service provides skilled nursing in a person's home. Services may include care, coordination of medical services, assistance with accessing other medical services and professionals and education about medical needs and supports.

Housekeeping: This service provides support for housekeeping tasks.

Intermediate Care Facilities for the Mentally Retarded: This service provides health and habilitative services to people with developmental disabilities. Services are provided in facilities in Maricopa County and at the Arizona Training Program at Coolidge.

<u>Medical Services:</u> Medical services are provided to people who are eligible for Long Term Care. Services include doctor visits, hospitalization, medications, hospice, etc. Also covered are dental services and diapers for children up to the age of 22 and hearing aids for children. See the "<u>Medical</u>" section of this guidebook for additional information about Medical Services.

<u>Nursing Facility</u>: This service provides skilled nursing care, residential care and supervision to people who need nursing services on a 24-hour basis, but who do not require hospital care under the daily direction of a physician.

<u>Respiratory Therapy:</u> This service provides treatment to restore, maintain or improve breathing.

<u>Respite:</u> This service provides a certified and trained individual to supervise and care for a person in order to relieve caregivers so they can go to a movie, out to dinner, take a vacation or even a nap. Respite may be provided overnight. This service may be provided in the person's or provider's home and may be provided by a licensed or registered nurse, if needed.

<u>Therapies - Occupational, Physical and Speech:</u> These services restore, maintain or improve functional skills, a physical function or communication.

<u>Transportation (Non-Emergency):</u> This service provides or assists in obtaining transportation, but does not include ambulance services. This may include transportation to therapy appointments or to day programs.

## What supports and services can I have?

All people and families have different requirements, therefore supports and services are based on needs, and in some cases, availability of money. All supports and services are designed and delivered to meet the needs of a person and family. A person's needs are determined through needs assessments and evaluations. For example, a therapist may evaluate and make recommendations for on-going therapy. A Support Coordinator will assess for other supports and services such as Attendant Care, Habilitation, etc. Natural supports, including family, community based services and resources should be used to the maximum extent possible.

Additional information about assessment may be found in Chapter 700 of the Policy and Procedures Manual. The manual can be read at a local Division office or through the DDD website.

## How are support and service decisions made?

Decisions about what supports and services a person receives are based on a team process. The team consists of the person, family and a Support Coordinator. Others such as therapists and other providers involved in the life of the person may be part of the team. Through the Individual Support Plan, the Individualized Family Service Plan or the Person Centered Plan process, the team reviews assessments and evaluations, identifies natural supports and assists in defining what additional supports or services may be needed to enhance the person's abilities.

Additional information about the planning process may be found in the "Planning for Supports and Services" section of this guidebook and in Chapter 800 of the Policy and Procedures Manual. The manual can be read at a local Division office or through the DDD website.

## Who provides the supports and services?

Supports and services may be provided by an individual, through a provider agency or the state. Another option that works well for many families and people is to use a friend, neighbor, or relative as a service provider. If this looks like the best option, a Support Coordinator can make a referral for assistance. Certain certification requirements are not necessary if the individual to be providing the support or service is a relative, however parents of minor children may not be paid to provide supports and services. In some cases, spouses may be paid to provide care.

## Who monitors the supports and services?

The person receiving supports or services and the family are the primary monitors of quality. Recipients know what is good and what is not. Monitoring may be by a variety of other people, depending on the support or service and the setting. Regardless of the support or service, or the setting in which it is provided, a Support Coordinator will also monitor. For people living in group homes, the home is licensed by the Department of Health Services and monitored by the Division. For people living at home, the primary monitor may be other family members. People living independently may be their own primary monitor.

Additional information about monitoring can be found in Chapter 1000 of the Policy and Procedures Manual. The manual can be read at a local Division office or through the DDD website.

## What if my needs change?

If needs change, the planning process resumes as described in "Planning for Supports and Services" in this guidebook as well as Chapters 700 and 800 of the Manual as noted previously.

## Where can supports and services be provided?

They may be provided in the person's home, in the community or in the provider's home, depending on the support or service.

## Where can I get more information about supports and services?

The above information about services is intended to be brief. Additional information about services can be found in Chapter 600 of the Policy and Procedures Manual. The manual can be read at a local Division office or through the DDD website.

## Who pays for the supports and services?

The State funded program is based on yearly appropriations from the Legislature. It covers individuals who meet the criteria described earlier. The other major source of funds is the Arizona Long Term Care System which is the Medicaid funded program for people with developmental disabilities who meet Long Term Care eligibility criteria. Long Term Care funding provides for long term and acute care services to individuals with developmental disabilities and who are at risk of institutionalization. Other funding sources may include Title XX, client contributions, and grants. Additional information may be found in the "Funding" section of this guidebook.

## Is there a charge for supports and services?

The Division may bill an individual or their family for a portion of the cost of supports and services based upon income and a sliding fee scale, if that individual is not covered by Long Term Care. Additional information about charges for supports and services can be found in the "Funding" section of this guidebook.

#### **FUNDING**

## How does the Division get money to pay for supports and services?

The Division is funded through state appropriations, Federal Medicaid monies from the Long Term Care Program through AHCCCS, charges for services and other revenue. Based on input from a variety of concerned groups and advocates, the legislature balances the Division's budget request against estimated tax revenue for the budget year and determines the amount the Division is to receive.

## What does it mean to be Long Term Care versus state only eligible?

All people are screened for potential eligibility for the Long Term Care Program when applying for supports and services from the Division, Not all people will meet the criteria for the Long Term Care Program.

The Division receives Federal funds for the Long Term Care Program. Long Term Care eligible people must meet certain requirements. A person must qualify both financially and medically. The Pre-admission Screening is the tool used by AHCCCS to assess and give a score to a person's functional and medical status. To meet Long Term Care financial screening criteria, an adult must have cash resources of less than \$2,000 and have a monthly income of not more than 300% of the maximum Supplemental Security Income benefit. Parental income may be waived for a child under the age of 18. The specific financial criteria are complicated. A referral should be made to the Long Term Care program if there are any questions regarding financial criteria.

To be eligible for *state only* funded supports and services means the person did not meet the criteria for Long Term Care eligibility. All supports and services that this person is authorized to receive are funded only by state funds. These limited funds are appropriated to the Division by the legislature.

## What is the Arizona Health Care Cost Containment System?

The Arizona Health Care Cost Containment System (AHCCCS) is Arizona's Medicaid Agency and the state's health care program for people who do not qualify for other health care. AHCCCS is sometimes referred to as the Arizona Health Care Cost Containment System and includes Title XVI, Title XIX, Title XXI Premium Sharing and state only funded programs. AHCCCS coverage includes:

- Acute care services including doctor visits, hospitalization, medications, durable medical equipment, laboratory and x-ray, specialty care, home health and family planning;
- Long term care services including home and community based services, nursing facilities, Intermediate Care Facilities for the Mentally Retarded, hospice, acute care services, case management and behavioral health;
- Payment of Medicare premiums, coinsurance and deductibles for people who are Qualified Medicare Beneficiaries Only (no services are provided AHCCCS), and
- Emergency services only for people who qualify for the Federal Emergency Services and State Emergency Services programs.

## Who is eligible for the Arizona Health Care Cost Containment System?

As mentioned earlier, eligibility is guided by Federal and state laws and regulations.

Eligibility is complicated. Contact AHCCCS at 602.417.4000 or 800.962.6690 for information.

## What is the waiting list?

The waiting list is a listing of people who need and are awaiting:

- Supports and services,
- Additional supports or services, or
- An increase in current supports or services that is not currently available because
  of funding or resource limitations or unavailability of a provider.

The purpose of the waiting list is to ensure available resources are evenly distributed to people and families statewide based upon prioritized needs. These priorities are:

- Emergency Need: Court ordered or a Support Coordinator finds substantiated abuse or neglect as determined by Adult or Child Protective Services or a death in the family or significant illness that would necessitate emergency placement.
- Immediate Need: Long Term Care services are needed within 30 days of a
  person's enrollment in the Arizona Long Term Care System or a family crisis
  exists were supports and services could prevent an out-of-home
  placement.
- Current Need: The Individual Support Plan Team identifies a need for supports and services that is unmet due to funding or provider availability.
- Future Need: Individual Support Plan Team identifies supports and services that will be needed between 12 months and 24 months from the date of the initial entry on the waiting list.

Resources are provided to people as they become available and according to these priorities.

## OTHER FUNDING SOURCES

# Are there other funding sources available?

Yes. Other sources include Individual and Family Assistance, the Supplemental Payments Program and the Client Services Trust Fund.

## What is Individual and Family Assistance?

This limited funding source provides direct payments to a vendor based on financial need. This fund source may be used for supports that the Division does not provide with the goal of keeping the person in the family home. It could be used for nutrition supplements, diapers, etc. Contact your Support Coordinator for additional information.

## What is the Supplemental Payments Program?

This program provides \$70.00 per month for housekeeping services to people who are not eligible for Long Term Care. Contact your Support Coordinator for additional information.

#### What is the Client Services Trust Fund?

The Client Services Trust Fund is an assistance fund that was established to assist people with developmental disabilities and their families in reaching increased independence. This fund is not for on-going expenses such as rent or utilities. The Developmental Disabilities Advisory Council (see the "Safeguards" section of this guidebook) is responsible for reviewing applications and awarding up to \$3,500 for planned expenditures that meet the program goals.

## How do I apply for the Client Services Trust Fund?

Complete an application and a financial need statement. Include the number of people living in the household and the total household income. Applications may be obtained through your Support Coordinator or by calling the Client Services Trust Fund Coordinator at 602.542.0419 or 866.229.5553 or on the web at <a href="https://egov.azdes.gov/cmsinternet/appforms.aspx?category=81">https://egov.azdes.gov/cmsinternet/appforms.aspx?category=81</a>. Awards are made two times per year.

The award process takes approximately 90 days from the application deadline. If awarded, applicants will receive a letter of award which will indicate any additional requirements to receive funding. Incomplete applications will not be considered for funding and will be returned. Reapplication with complete information may be made at the next award cycle. Applicants should submit any additional documentation such as estimates or letters of justification to assist the Developmental Disabilities Advisory Council in evaluating the request. At least two estimates must be included for such things as car repairs, home modifications or home repairs.

A Support Coordinator can provide assistance in completing this application.

## What is covered by the Client Services Trust Fund?

The Council will review and authorize expenditures for single item, one-time requests that assist a person to more fully participate in community life or increase quality of life, up to the limit of available funds. The Client Services Trust Fund does not cover ongoing needs such as rent subsidies or therapies. The Council is unable to fund the purchase of vehicles, but may cover the cost of repairs or modifications to vehicles.

#### Whom do I contact?

For information about the Client Services Trust Fund, call 602.542.0419 or 866.229.5553 or visit the DDD website.

## **PILOT PROGRAMS**

# What is the Division doing to continually review and improve its systems and processes?

The Division's key to success is to exceed the expectations of its customers. One way the Division demonstrates the commitment to exceed expectations is to continually review Division systems and processes. Stakeholders provide important input and can often assist the Division in identifying ways to offer more choice, control and satisfaction with supports and services delivery. The Division conducts a demonstration or pilot project before new ideas are implemented or existing programs are changed.

## What is a pilot or demonstration project?

A pilot or demonstration provides an opportunity to test theories and work out bugs, something like a science experiment! The Division uses pilot projects as a way to determine if the proposed changes are helpful and useful to people, and to test whether it is cost effective and practical to implement further.

#### How do I learn more or participate?

Learn more about the current pilot and demonstration projects through the Division's website or by contacting a District Program Manager.



# THE EARLY YEARS

Parents or other individuals involved in a baby's life recognize the first years are when the most significant development occurs. This is why it is important to know that supports and services are available to assist infants and toddlers from birth to age three. The following information describes early intervention and transitioning to preschool. Further information can be found through your Support Coordinator or at <a href="http://www.azdes.gov/azeip/">http://www.azdes.gov/azeip/</a> or by calling 602.532.9960 or 888.439.5609.

## What is early intervention?

Early intervention is a process in which a group of professionals, such as therapists and educators, work in partnership with parents and families of children with special needs to support growth, development and learning.

## How can it help my child and family?

The first three years of a child's life are critical years for learning. Early care and education have a long lasting impact on how children develop. During a child's early years, it is important to focus on the child's developmental needs and to take advantage of the child's natural ability to learn by supporting the family.

## Who is eligible?

Any child from birth to three years of age who has a developmental delay or an established condition that has a high probability of resulting in a developmental disability.

## What is the role of a Support Coordinator during these early years?

A general definition of a Support Coordinator is found in the "Overview" section of this guidebook. During the early years, a Support Coordinator will also facilitate the development of an Individualized Family Service Plan as well as a transition plan for preschool services.

## What is an Individualized Family Service Plan?

An Individualized Family Service Plan describes the supports and services a child and family will receive to help with growth and development. It is developed by a team and identifies desired outcomes.

#### What kinds of early intervention supports and services are available?

Supports and services are planned to meet the needs of each child and family and might include hearing services, home visits, nutrition services, occupational, speech or physical therapy, family counseling, vision services or others.

## What if I disagree with the proposed supports and services?

The issue resolution process is described in the "Safeguards" section of this guidebook. For more information visit <a href="https://www.azdes.gov/azeip/safeguard.asp">https://www.azdes.gov/azeip/safeguard.asp</a> or contact your Support Coordinator.

## Is there a charge for services?

No.

## What is an Early Interventionist?

An Early Interventionist is a specially trained individual who assists a family in supporting child development. Specific activities the Early Interventionist may carry out might include evaluations, coordinating supports, providing information and referral.

## What is a "Natural Environment" and why is it important?

Natural environments are settings that are normal for a child's age amongst peers who have no delays or disabilities. Services and supports provided in natural environments are a part of the family and child's daily activities and routines and promote integration of a child and family into the community.

# What happens when my child turns three and is no longer eligible for early intervention?

When your child is two years and six months old the team can begin the transition process to preschool and from there to kindergarten. School Districts are responsible to provide special education to all eligible children.

# What is an Individualized Education Program and how is it different from our Individualized Family Service Plan?

The Individualized Family Service Plan defines goals in developmental terms. The Individualized Education Program defines goals in educational terms. Regardless of what the plan is called, all plans focus on a child's growth and development. For additional information about Individualized Education Programs, see "The School Years" section of this Guidebook.

# What will my child's school program look like?

A child's education will be based on the Individualized Education Program and will include all identified supports, services and accommodations. The experience is different for each child; it may be an education in a variety of settings. It could be in a regular classroom with identified supports. It could also be in a resource class or perhaps a self-contained class. Every member of a child's Individualized Education Program team will help determine the most appropriate setting for a child to receive the identified educational supports and services.

# What are some of the educational supports, services and accommodations my child might receive?

These could include transportation, therapies, adaptive physical education, nursing, etc., but will depend on your child's needs.

## How can I learn about special education laws?

You can learn about special education laws from a variety of sources including:

The Arizona Center for Disability Law 602.274.6287

800.927.2260

http://www.azdisabilitylaw.org

Raising Special Kids 602.242.4366

800.237.3007

http://www.raisingspecialkids.org

Pilot Parents of Southern Arizona 520.324.3150

877.365.7720

http://pilotparents.org

Department of Education 602.542.4013

Exceptional Student Services http://www.ade.az.gov/ess/

Wrightslaw http://www.wrightslaw.com



# THE SCHOOL YEARS

The years your child spends in school can be some of the most exciting and the most challenging. Your child will have opportunities to learn new skills, experience new things, receive educational supports and services and make new friends. The best thing that parents or other individuals involved in a child's life can do is become educated about a child's right to a free and appropriate public education, and about the Federal requirements a school must meet to comply with the Individuals with Disabilities Education Act. This section of "Navigating the System" provides information on special education and your child's Individualized Education Program.

## What is Special Education?

Special Education ensures that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living. Special Education is mandated by the Federal Individuals with Disabilities Education Act (IDEA), a copy of which can be obtained from the Department of Education, Exceptional Student Services, at the website <a href="https://www.ade.az.gov/ess/idea/reauthorization/default.asp">www.ade.az.gov/ess/idea/reauthorization/default.asp</a> or by calling 602.542.4013.

## What are the eligibility requirements for special education?

Eligibility categories include:

- Mental Retardation:
- Hearing impairment;
- Speech or language impairment;
- Visual impairment;
- Emotional disturbances;
- Orthopedic impairments;
- Autism;
- Traumatic brain injury;
- Other health impairments; and
- Specific learning disabilities.

## Is financial status considered? Are there charges?

No. Every child found eligible for special education has the right to a free, appropriate public education.

#### What information should I have available?

Copies of any medical records, any evaluations such as therapy or psychological and documentation of all disabilities or special needs your child may have.

## What if I don't have any evaluations? Would I have to pay for them?

No. A written request for evaluation for special education will require a school to do a comprehensive educational evaluation of your child in the area of suspected disability within 60 days.

## What if I don't agree with the evaluation?

You have the right to request a independent evaluation paid for by the school. The school must provide you with a list of independent evaluators. You are also free to choose someone who is not on the list.

## What happens after the evaluation is completed?

A multi-disciplinary team will meet to determine eligibility for special education. You will be part of that team, at some point.

## What happens then?

The team will decide appropriate placement in services. Remember that special education is not a place. It is individualized supports to give children with disabilities the extra help they need to learn in the general classroom.

## What is an Individualized Education Program?

An Individualized Education Program is a plan that describes in detail the goals for a child's education and includes specific supports and services that will be provided. A team develops it. The program should include a statement of your child's present level of performance. It should include all supports and services to be received including the amount and frequency. It should also include goals your child will be working on. The Arizona Center for Disability Law at 602.274.6287 or 800.927.2260 or the Department of Education at 602.542.4013 can provide detailed information regarding Individualized Education Programs.

#### Who is on the team?

Minimally, the team must be multi-disciplinary and include:

- The child, if appropriate;
- The parent(s);
- A special education teacher;
- A regular education teacher;
- A representative of the school system who has the ability to commit resources; and
- Someone with the ability to interpret test results.

## Who else may be on the team?

- An individual with special knowledge or expertise about the child which may include a family member, friend, advocate or anyone else with whom you are comfortable, or
- Other school personnel, as appropriate.

## What is the role of a Support Coordinator during the school years?

A general definition of a Support Coordinator is found in the "Overview" section of this guidebook. A Support Coordinator can also attend school meetings with you and can coordinate the Individual Support Plan with the Individualized Education Program. You must invite your Support Coordinator if you want them to attend.

## This is all new to me. What should I expect at this team meeting?

You are is an equal member of the team and your child is unique (Who knows them better?). Write down your child's goals and concerns and take them along. Be ready to discuss your child's likes and dislikes. The school personnel may bring a draft plan, however your input must be considered in developing the final plan.

## Where will my child be educated?

"Least restrictive environment" is the phrase used in law to describe the class where a child with a disability will be provided services. It means placing the fewest possible restrictions on the time spent with children without disabilities. The law intended learning to happen in the general classroom where all children are welcomed and valued even if they are different. All students may see that getting and giving help is okay.

Children with disabilities start out in the general classroom with supports if needed. If spending the whole day in a general classroom will not work, the child might go to a resource room or work with a therapist for parts of the day. If other options are not appropriate, a child may spend the entire day in a separate special education classroom.

## What if my child needs other supports and services while at school?

Other supports and services must be provided by the school. These could include therapies, medical support, assistive technology or specialized transportation.

#### What educational modifications or accommodations are available?

The list is endless and is based on your child's needs. Modifications and accommodations may be very simple such as providing both written and spoken direction, or extra time on tests and assignments. Others may include work being done through a computer or verbally.

## How often will I be informed about my child's progress?

You must be informed at least as often as parents of children in regular education. This is typically "Report Card" time.

#### What is Extended School Year?

As part of each child's Individualized Education Program, the need for additional schooling over the summer must be addressed to ensure a free appropriate public education. Public schools must provide extended school year services if:

- (1) The benefits that the pupil gained during the regular school year would be significantly jeopardized if the pupil is not provided educational services; or
- (2) The pupil would experience severe or substantial regression if the pupil is not provided educational services during recesses or the summer months and the regression would result in substantial skill loss of a degree and duration that would seriously impede the pupil's progress toward educational goals.

## What if the team can't agree on what my child's program should include?

Always attempt resolution at the lowest level possible first. This means working with the teacher, principal of the school or the district's special education director. If the issue still has not been satisfactorily addressed, mediation may be requested through the Department of Education.

#### What is mediation?

A trained, impartial mediator will meet with all concerned people and try to help them come to agreement. If agreement is reached, a plan will be written and all parties will sign this plan.

# What if agreement isn't reached through mediation or the mediation agreement isn't followed?

Request a Due Process Hearing. This hearing will occur in front of a Hearing Officer and will most likely include an attorney on behalf of the school district. You may wish to contact the Arizona Center for Disability Law at 602.274.6287 or 800.927.2260 or the Department of Education at 602.542.4013.

## How can I learn more about the Individualized Education Program process?

Information about the Individualized Education Program process can be obtained from:

Arizona Center for Disability Law 602.274.6287

800.927.2260

http://www.azdisabilitylaw.org

Department of Education 602.542.4013

http://www.ade.az.gov/ess

Raising Special Kids 602.242.4366

800.237.3007

http://raisingspecialkids.org

Pilot Parents of Southern Arizona 520.324.3150

877.365.7220

http://pilotparents.org

## What is the Department of Education and how does it fit in?

The Arizona Department of Education is administered through the State Board of Education. The Board is the governing and policy setting entity of the Department. The Department of Education has the legal responsibility to carry out the requirements of the Individuals with Disabilities Education Act (IDEA, Public Law 108-446), formerly the Education for all Handicapped Act. Exceptional Student Services, within the Department of Education, has been assigned the responsibility to ensure that all Arizona children with disabilities have access to a free appropriate public education.

#### Exceptional Student Services duties include:

- Providing information and technical assistance to local and private education agencies, other state agencies and the community;
- Determining compliance with state and federal laws and regulations;
- Distributing state and federal funds;
- Developing and supporting innovative projects; and
- Assuring that appropriate training is available for those concerned with the education of children with disabilities.

#### How do I contact them for more information?

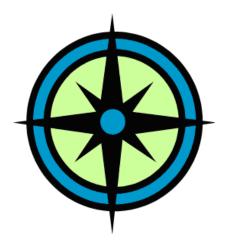
Telephone 602.542.4013 or visit the website http://www.ade.az.gov/ess

# What is Medicaid in the Public Schools and will it affect services my child receives through the Division?

Medicaid in the Public Schools is a method to maximize Federal dollars for certain services. Utilizing this program will not affect a child's services through the Division. The Department of Education can provide more information about this program. Call 602.542.4013.

# Are summer programs available through the Division?

Children may require ongoing supports to continue skill development while out of school. The Division may provide a day program to provide these supports. Summer programs are not a substitute for day care. Transportation to and from the summer program is available, if needed.



# THE YOUNG ADULT YEARS

As your child nears the end of the school years, there are important issues you must be aware of and plan for so that the school years are both productive and prepare your child to enter adulthood. This section of "Navigating the System" provides information to help ensure the transition from high school to adulthood allows your child an opportunity for progress in achieving their goals and vision of life after school.

# What is the transition process that the school is responsible for developing and implementing?

Transition is a process that helps define goals from high school to adulthood. It includes planning through the Individualized Education Program and should address all the needed supports and services to make a smooth and productive transition out of school. It should also include a description of supports that may be needed after graduation.

# When does it begin?

At age 14 the Individualized Education Program should state the types of things your child needs to learn in the classroom to be ready for transition activities. These may include community training, employment skills, etc. Transition activities such as work experience must begin at age 16.

# What is the role of a Support Coordinator during high school and the young adult years?

A general definition of a Support Coordinator is found in the "Overview" section of this guidebook. During high school and the young adult years a Support Coordinator will also be working with parents and the Individualized Education Program team to ensure that all transition activities are occurring as defined in the program and that supports and services are preparing the child for adulthood.

## What things should the transition plan address?

The transition plan should address your child's goals or vision of what happens in the following areas after graduation, based on preferences and interests:

- Employment;
- Community participation and mobility;
- Recreation and leisure:
- Post-secondary training and other learning opportunities; and
- Independent living.

The transition plan must define your child's current abilities and needs relative to the areas noted above. The transition plan should be meaningful to your child and contain strategies to help meet goals. It must identify agencies and/or individuals who will be involved in the goals including those who will pay for any needed services.

## What is the school's responsibility in making transition work?

The school is responsible to ensure the Individualized Education Program defines all the needed supports and services and that all are provided appropriately.

## Where can I find more information about transition planning?

Contact a Parent Information Network Specialist at the Department of Education 602.364.4015 or 800.352.4558 or visit the http://www.ade.az.gov/ess/specialprojects/pinspals/. Information may also be obtained through the Arizona Department of Education Transition Services at 602.364.4026 or on the website http://www.azed.gov/ess/SpecialProjects/transition/. There is more information about the role of Vocational Rehabilitation in transition planning at the website www.azdes.gov/rsa/transition.asp.

## How long can my child stay in school?

Your child has the right to stay in school until the age of 22. However, sometimes schools encourage students to graduate with their class. This is not necessary; your child can participate in graduation ceremonies without getting the diploma or certificate until later.

# My child is 18 and I've been told I can't participate in the Individualized Education Program any longer. Is this true?

No. Your child may sign a Power of Attorney for Educational Purposes to allow you to continue to be part of the team. Additionally, your child may invite anyone with special knowledge or expertise and this certainly includes you.

## What else happens when my child turns 18?

Eligibility for Division services is re-determined prior to your child's 18 birthday. If your child is male, he must register for the draft, regardless of his disability. An 18 year-old may register to vote and is legally able to represent him/herself in all matters such as renting an apartment or making medical decisions. Please refer to the "Guardianship" Section of this Guidebook for additional information.

# I've been involved in parent groups. Are there groups for adults with developmental disabilities?

Currently, there are several independent living centers in Arizona. These centers can help find groups for adults with developmental disabilities. They are:

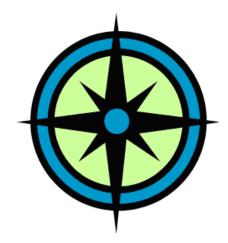
ABIL 1229 E. Washington Street Phoenix, AZ 85034 602.256.2245 800.280.2245 http://www.abil.org

ASSIST to Independence
Box 4133
Tuba City, AZ 86045
520.283.6261
888.848.1449
http://www.nau.edu/ihd/aztap/assist.html

New Horizons 8085 E. Manley, Ste. 1 Prescott Valley, AZ 86314 928.772.1266 800.406.2377 http://newhorizonsilc.org DIRECT Center for Independence 1023 N. Tyndall Ave Tucson, AZ 85719 520.624.6452 800.342.1853 http://www.directilc.org

SMILE 1929 S. Arizona Ave, Ste. 12 Yuma, AZ 85364 928.329.6681

Virtual Center for Independent Living <a href="http://www.cybercil.com/">http://www.cybercil.com/</a>



# THE ADULT YEARS

This stage of life is when a person may have completed high school, or soon will, and is ready to meet the continuing challenges and adventures of life. This may mean deciding whether to explore the possibilities of getting a job or identifying the skills that will be needed to live and work more independently in the community. In our society, young adults often move out of the family home and this may be a goal you are discussing and exploring. Or perhaps your family member has worked and is now ready for a retirement program. Other issues of great importance and significance also loom: Guardianship, wills, trusts, and home ownership. Perhaps there is concern for what will happen to your family member when you no longer are able to care for them.

This chapter of "Navigating the System" contains information on many issues including guardianship, wills and trusts, a change in residence from a family home, day programs, retirement, and aging caregivers. Staff of the Division, including your Support Coordinator, are ready to assist if any issue is not addressed.

## What is the role of a Support Coordinator during the adult years?

A general definition of a Support Coordinator is found in the "Overview" section of this guidebook. While continuing to provide the same supports that have been provided, a Support Coordinator will also help in explaining legal considerations, exploring living options and day or work opportunities where needed. This may include identifying resources for further skill development to enhance independence, and identifying opportunities to have fun and make new friends.

#### **LEGAL CONSIDERATIONS**

#### What are the legal considerations when my child turns 18?

Planning is essential to ensure your child is provided for once you are gone. This may be in the form of a will, trust, guardianship, etc. It will vary for each family. Contact an attorney or financial planner for help writing a will or establishing a trust.

As your child nears the age of 18, part of the annual review process will include evaluating the need for a guardian. A child of 18 years or older has all the legal rights of an adult unless a legal guardian has been appointed by a court. A Support Coordinator will help you understand the need, as well as the process, for obtaining a guardian.

# What is guardianship?

Guardianship is a legal method used to ensure that a person who is unable to make decisions has someone specifically assigned to make decisions on their behalf. A court appoints a guardian only after reviewing "clear and convincing evidence" that the appointment is necessary. Appointment of a guardian is serious legal action not to be undertaken lightly.

## Do people with developmental disabilities have to have a guardian?

No. Not all people with a developmental disability need a guardian. Under Arizona law, an individual with a developmental disability is presumed legally competent. That means independent consent can be given for things like medical treatment, contracts, program decisions and release of confidential information. Only a court, through review of information presented, can make a determination that an individual is unable to independently care for basic health and safety and is unable to make informed decisions. Guardianship should only be used to the extent necessary to promote the well being of an individual.

# Do people with developmental disabilities have to have a guardian to apply for eligibility determination from the Division?

No. Parents of minor children may apply on a child's behalf; adults who do not have a guardian can apply for eligibility determination. A guardian may apply for an eligibility determination on behalf of a person.

## Why might the appointment of a guardian be necessary?

A determination must be made relative to the need for a guardian if there is serious doubt regarding an individual's ability to make or communicate responsible decisions.

## Who can be a guardian?

Any competent individual may be appointed guardian by a court but certain people take priority over others. People who have priority include the person's parents, adult brothers or sisters, or another family member such as a grandparent, aunt, uncle or cousin. Often, parents will designate a person in a will to be responsible to carry out this duty after them. If no one has been identified or shows interest in becoming a person's guardian, a Public Fiduciary is appointed.

#### Are there different levels of guardianship?

There are different levels of guardianship. Perhaps the person needs assistance to help make decisions in the management of money only, or assistance when making health care decisions. In those cases, perhaps limited guardianship is needed.

#### Is a conservator different from a guardian?

A conservator is an individual appointed by a court to manage the estate of a protected person. A person may have a guardian, a conservator or both.

## What if a medical emergency occurs and there is no appointed guardian?

An adult cannot consent to medical treatment if the understanding to make responsible decisions is lacking. If a guardian is unavailable (due to resignation or death), Arizona law allows other specific individuals to act as surrogate and to sign consent for medical treatment. If an immediate and life-threatening emergency exists, the attending physician, after consulting with a second physician, may make the health care treatment decision without signed consent. Additional information about this may be found in Section 1503.2 of the Division's Policy and Procedures Manual. The manual can be read at a local Division office or through the DDD website.

## How is "power of attorney" granted?

Granting someone "power of attorney" does not require court action. Simply write down what the power of attorney is for, such as assistance with health care decisions. The document must be signed, witnessed and the signatures must be notarized. It is recommended that an attorney be consulted before drawing up legal documents.

## What is a Public Fiduciary?

When a parent, other family member or close friend is unwilling or unable to act as guardian, it may be necessary and appropriate for a public guardian, known as a Public Fiduciary, to be appointed. There is a charge for this service which is provided by the counties.

## What is a Private Fiduciary?

A Private Fiduciary is an individual or organization that performs guardianship duties for a fee.

## I have heard the term "surrogate parent" used. What does the term mean?

If a child is in foster care and has no parent able or willing to participate in the educational process, a surrogate parent will be appointed to represent that child in decisions related to education. This individual is an equal member of the team and participates in all decisions about the child's education.

## What is a "representative payee" and how is that different from a guardian?

The term 'representative payee' relates specifically to an individual designated by the Social Security Administration to manage Social Security Income and/or Supplemental Security Income payments on behalf of a person who has been determined to need support in handling their finances. A person can have both a guardian and a representative payee or just a representative payee. Contracted service providers may not be representative payees nor may agency board members. Agency board members may, however, be representative payees for their own family members. The representative payee is responsible for deciding how an individual's Social Security and/or Supplemental Security Income is spent.

# What are the duties of a guardian?

A guardian's duties are similar to those of a parent and might include making decisions such as finding the most appropriate and least restrictive setting consistent with the person's needs or making reasonable efforts to secure medical, psychological or social services for the person. A guardian must be involved in the development and monitoring of the Individual's Support Plan to ensure supports and services are appropriate and adequate. The court also requires periodic reports on the welfare of the person.

## Does a guardian need to live near the person?

A guardian must be willing and able to provide oversight of the individual's care and resources. Some guardians live out of state but are able to devote the necessary time to carry out the responsibilities, including all required reports to the court. Using today's technology, Division staff can communicate with guardians through various means in order to keep them informed and involved.

## What rights does an individual lose when a guardian is appointed?

Appointment of a guardian limits the rights of the person who is legally known as a ward. A ward loses some rights including making independent decisions about residence, program involvement and medical care. Even day-to-day activities could be impacted including decisions about personal associations or involvement in social events. Specifically, a ward will not have the right to vote, hold a driver license, choose a residence or how to invest money, or to take, or not take, medication. It is very important to carefully examine the extent or need for guardianship.

## Do I need the services of an attorney in order to pursue guardianship?

No. An attorney is not required. Many counties have a Self-Service Center, typically located at the Supreme Court. Self-Service Centers have the required forms to file for guardianship without an attorney. Forms can be picked up from a Self-Service Center, completed and filed independently. Additional information may be found at the website <a href="http://www.supreme.state.az.us/selfserv/">http://www.supreme.state.az.us/selfserv/</a>.

#### How do I plan for an emergency?

Discussing concerns in advance of an emergency with other family members or friends may be appropriate. Concerns and desired outcomes may also be defined through an Individual Support Plan.

#### Whom can I contact for more information?

There are a number of resources available in the area of guardianship. The Guardianship Service Commission, a subsidiary of The Arc of Arizona was created to protect the human and legal rights of individuals with developmental disabilities through a systematic approach to advocacy and protective services (see chapter on Safeguards). The Commission can assist in appropriately performing guardian responsibilities. It presently provides guardianship for a number of people with developmental disabilities. Although The Arc does not recommend or endorse any attorney or financial planner, they do maintain lists of those who are willing to accept referrals. You may contact the Guardianship Coordinator at 602.234.2721 or 866.501.2721 or visit the website <a href="http://www.arcarizona.org/">http://www.arcarizona.org/</a> for more information.

Additional information about legal service organizations throughout Arizona can be found in the People's Info guide published by the Arizona Community Action Association. Telephone 602.604.0640 or visit website <a href="http://www.azcaa.org/">http://www.azcaa.org/</a>

The Governor's Council on Developmental Disabilities has prepared a "Legal Options Manual" that describes available options concerning individuals over the age of 18. The manual can be read on the website <a href="http://www.azgcdd.org/legal\_manual\_intro.asp">http://www.azgcdd.org/legal\_manual\_intro.asp</a> or telephone the Council at 602.277.4986 or 866.771.9378.

## LIVING OPTIONS

# My family member wants to live at home. What supports are available to us?

A person may have such services as habilitation, day treatment and training, etc., based on assessed need and as identified in the Individual Support Plan. See the "Overview" section of this guidebook for more information on services.

#### My family member would like to move out of our home. What options are there?

Planning is key in addressing this important step. The needs and preferences of your family member as well as your own, are important when considering or planning a move. There are a variety of living options available. These include group homes, semi-independent settings, adult developmental homes, individualized living arrangements and in some cases, assisted living. Your Support Coordinator can help in understanding the options available.

# Is there a waiting list for these settings?

Yes. People seeking a residential placement will have their needs reviewed and prioritized and then will be placed on a waiting list. There is no way to give a timeline as every person and their needs are unique.

# Can I tour group homes or other residential options?

Yes. This can be arranged through your Support Coordinator.

# Can my family member choose with whom they will live?

The Division makes every effort to accommodate this request but it is not always possible. The Division does work with teams to ensure that people are as compatible as possible. If a person is moving into a newly created home, the opportunity is greater to have some choice in roommates.

#### Can we meet the other individual's family members?

Absolutely. If the team finds an existing home and other individuals' family members are willing, you may meet them. Families can meet prior to moving in to a newly created home.

### Who monitors these settings?

There is routine monitoring by the Support Coordinator depending on the type of setting. Other Division staff routinely monitor all settings. Group homes may also be monitored by The Arc of Arizona. If you would like to volunteer with the Arc of Arizona, contact them at 602.234.2721 or 866.501.2721 or through the website <a href="http://arcarizona.org">http://arcarizona.org</a>. Group homes and assisted living facilities are licensed by the Department of Health Services.

### Who provides these services?

Contracted agencies operate group homes and other supported settings. Support services may be provided by agencies or by individual providers for people living independently. Adult developmental homes are family homes that provide supports and are open to three people at most.

#### Is there a charge?

Typically, an individual is billed for 70% of Supplemental Security Income to offset room and board expenses.

#### Why is my family member charged to live in a residential setting?

State law says that the Division may require individuals who are receiving residential services and who receive income or benefits to contribute to the cost of their support. It also states that an individual shall retain a minimum of 30% of income or benefits for personal use. The Division has a rule that allows individuals who are living in a group home or adult developmental home to keep the first \$50 or 30% of benefits, whichever is greater, and the remainder is billed by the Division for the cost of services.

Income is not billed, only benefits received by the individual which include Social Security payments, Railroad Retirement, Veteran's Benefits, etc. This is called residential billing and the funds are used to provide services to additional individuals.

A review of the residential billing may be requested. A request will be reviewed by the District Program Manager/Administrator who will then forward it to Central Office for final approval. It is important that the financially responsible individual keep the Division updated on any changes in benefits to assure accurate and timely billing.

# What are the qualifications and training of the staff that provide supports and services? Is there a background check?

Staff must be 18 years or older, provide references from people other than family members, have knowledge, skills and experience to meet the requirements of the job and have a fingerprint clearance.

All staff must have Cardio-Pulmonary-Resuscitation (CPR), first aid training and have an orientation to the specific needs of people living in the setting. Other training requirements can be reviewed at the website <a href="http://www.azsos.gov/public\_services/Title\_06/6-06.htm">http://www.azsos.gov/public\_services/Title\_06/6-06.htm</a> at R6-6-808 or contact the Secretary of State at 1700 West Washington, 7th Floor, Phoenix, AZ 85007-2888, 602.542.4285 for a copy of the applicable rules.

# What are the licensing and monitoring standards for group homes?

Monitoring rules maybe found at http://www.azsos.gov/public\_services/Title\_06/6-06.htm in Article 8. Licensing rules may be found at http://www.azsos.gov/public\_services/title\_09/9-33.htm. You may also contact the Secretary of State at 1700 West Washington, 7th Floor, Phoenix, AZ 85007-2888, 602.542.4285 for a copy of these rules.

#### DAY PROGRAMS

#### What are day programs?

Day programs offer a variety of activities including opportunities for socialization, volunteering, going to movies or shopping. Older individuals may choose to participate in a local senior program to experience positive interaction with peers.

### What would my program look like?

Your program would be defined through an Individual Support Plan and may include work training activities, volunteer opportunities, community experiences or whatever meets your wants and needs.

# Do I have the right to express my preference for my day program?

Yes. It is your right to express preferences for a day program based upon available options.

# Is transportation provided to and from the day program?

This would be defined through your Individual Support Plan and may include the use of public transportation.

# Who provides day programs?

Day programs may be provided through contracted agencies or may be available through local community resources.

### Is there a charge for day programs?

There is no charge for a Long Term Care funded program, however individuals who are not Long Term Care eligible may be assessed a charge. There may be a charge for certain community activities regardless of the type of funding.

#### How do I find out more information?

Contact your Support Coordinator to discuss options.

#### **EMPLOYMENT OPPORTUNITIES**

# How do I become involved with the Division of Developmental Disabilities Employment Supports and Services program?

The process begins with an Individual Support Plan team identifying the need for employment services. In some cases this will involve first going through the Rehabilitation Services Administration's Vocational Rehabilitation program.

#### What is the Rehabilitation Services Administration and Vocational Rehabilitation?

The Rehabilitation Services Administration is the Department of Economic Security program that provides rehabilitation services to individuals who have disabilities that present barriers to employment and the ability to live independently. Vocational Rehabilitation is the part of the Rehabilitation Services Administration that assists individuals with disabilities to overcome barriers to employment and become as economically independent as possible.

#### How are Employment Supports and Services funded?

The majority of Employment Supports and Services are funded through the Arizona Long Term Care System. Based on the availability of funding, people who are not Long Term Care eligible may still receive limited assistance with employment related services.

# What will happen to my Social Security, Long Term Care or other benefits if I get a job?

Social Security benefits and benefits provided through Long Term Care are impacted by income and assets, so the amount of income earned may affect your benefits. There are agencies that will assist you in determining what effect, if any, your employment income will have on your benefits. Contact a Work Incentive Specialist at your local Independent Living Center through the AZ Freedom to Work Statewide Benefits Planning, Assistance and Outreach Project at 866.304.WORK (9675).

### What kinds of jobs are available?

Job opportunities are based on work experience, education, abilities, interests and availability of employment within the local community. Working with a Vocational Rehabilitation Counselor will help you in exploring and identifying an appropriate job.

# Are there a minimum number of hours that I am required to work?

Currently, Vocational Rehabilitation requires a minimum of 10 working hours per week to be considered gainfully employed. However, the Division of Developmental Disabilities has no limitations for the Employment Supports and Services Program. Your work schedule is determined by a number of factors including individual circumstances, the Individual Support Plan team and an employer's needs.

# What if I need extra training or education for the job?

Extra training/education should be discussed and identified by your Individual Support Plan Team and the Vocational Rehabilitation Counselor.

# How will I get to and from work?

Public transportation may be necessary, or the need to rely on the assistance of family, friends, neighbors, co-workers, etc. Your Individual Support Plan team will help explore all available options, which may include transportation funded through the Division of Developmental Disabilities.

#### How much support will I receive when working?

Each person will receive the type and amount of support necessary to remain successfully employed, as identified by an Individual Support Plan team. The Team may also help to develop "natural supports" that can supplement or even replace funded services, e.g. a friendly co-worker who might be willing to act as a mentor at the workplace.

#### Can I choose to work part-time and participate in other activities?

Yes. Working part-time and participating in other activities such as a day treatment program or other community activities is possible. The number of working hours may vary depending upon financial needs, abilities, any health issues, and the availability of part-time employment.

# How long will the Division of Developmental Disabilities provide extended employment supports to me?

The Division of Developmental Disabilities will provide Employment Supports and Services for as long as required. These supports are subject to regular review, as are all services, and may be modified as your team deems necessary.

#### What is the role of Vocational Rehabilitation?

The Vocational Rehabilitation Program becomes a potential partner with the Division when:

- An individual's goal is consistent with the mission of the Vocational Rehabilitation Program;
- The type of employment the individual is seeking meets their definition of employment: and
- The individual is in need of vocational rehabilitation services in order to attain an employment goal.

The Division makes a referral to the Vocational Rehabilitation Program for eligibility determination when mutually agreed conditions exist.

Services provided by a Vocational Rehabilitation Program may include but are not limited to vocational evaluation, job training, job search, job placement, transportation, job site modification, self-employment and entrepreneurial activities. If an individual requires extensive follow-along employment support services after completion of a vocational rehabilitation program, resources to pay for such supports must be pre-identified when the Division makes a referral. The Division works closely with the Vocational Rehabilitation Program and has developed principles of cooperation and collaboration as well as policies and procedures for information sharing, referral and joint planning activities.

# **MEDICAL**

This section of "Navigating the System" provides information on medical services, including medically necessary equipment, aids and devices provided to people who are Long Term Care eligible or eligible for health care through Arizona Health Care Cost Containment System. It also provides information on medical services for foster children who are not eligible for Long Term Care services.

#### What about my medical care?

If you are eligible for Long Term Care, the Division provides medical care through contracted health plans or Indian Health Services. If you are not eligible for Long Term Care, health care may be available through AHCCCS. Foster children who are not eligible for Long Term Care receive medical care through the Comprehensive Medical and Dental Program.

#### What if I have other medical insurance?

Other medical insurance must used before Long Term Care coverage. If that insurance requires co-payments, your Long Term Care Health Plan will reimburse you the cost of those co-payments.

#### What is Third Party Liability?

Third Party Liability describes resources, other than those provided by the Division, which may pay for care and services for the person. Think of yourself as the first party, the Division as the second party and any other payment sources, such as private medical insurance, as the third party. Private medical insurance may include Medicare, TriCare or Health Maintenance Organizations such as United Healthcare or Cigna. Even though private medical insurance is called "Third Party Liability" or TPL, it is the primary payer as the Division is the payer of last resort.

# How does it apply to me?

If you have other health insurance, the Division must bill the insurance for certain services such as therapies or medical services. If you have other benefits or a monetary settlement as the result of an accident, these sources may also be billed for certain services.

Your Support Coordinator will work with you to determine how Third Party Liability may apply to you. Once you provide the Division with information about insurance or settlements, the Division will take care of the rest.

#### Where can I get additional information about Third Party Liability?

Additional information about Third Party Liability may be found in Chapter 1200 of the Policy and Procedures Manual. The manual can be read at a local Division office or through the DDD website.

#### Who coordinates the medical care?

Everyone eligible for Long Term Care or an Arizona Health Care Cost Containment System health plan will have care provided and coordinated by a Primary Care Physician. Your Primary Care Physician will make appropriate referrals for specialty care, prescribe medications and order certain services such as therapies or special equipment, etc.

#### What is the role of the Support Coordinator relative to medical care and services?

A general definition of a Support Coordinator is found in the "Overview" section of this guidebook. A Support Coordinator can also assist in working with a Primary Care Physician in coordinating medical care.

# What if I am unhappy with medical care?

Talk to your Primary Care Physician first. If you are still not satisfied, read the health plan or Long Term Care member handbook to determine the next steps to take.

#### What if I have questions about my medical care?

Consult the health plan Member Handbook or contact your Support Coordinator, physician or health plan.

# Are dental and vision services and hearing aids covered?

Dental and vision services and hearing aids are covered for children up to 21 through the Early, Periodic Screening, Diagnosis and Treatment Program for those eligible for Long Term Care or an AHCCCS health plan. Preventive dental care up to \$1000 per year is covered for adults who are eligible for Long Term Care or an AHCCCS health plan.

#### I'm going into the hospital. Is there someone I should notify?

Notify your Support Coordinator who will assist with discharge planning as needed and can help ensure continuity of care after getting out of the hospital.

# What happens if I need nursing or equipment after I am discharged from the hospital?

This should be addressed in the discharge plan, but be sure to involve your Support Coordinator in that process.

As part of the discharge plan, discuss any special things that may be needed at home to make it more efficient for receiving care. This may include determining which room in the house is most suitable for any specialized equipment or getting extra fire extinguishers.

#### What is Durable Medical Equipment?

Durable medical equipment includes such things as wheelchairs, ventilators, feeding pumps, etc.

# How do I get it?

Typically, your Primary Care Physician or a doctor at Children's Rehabilitation Services will identify the need for, and make arrangements to obtain needed equipment. If training for you or your caregiver is needed, the equipment provider will provide it.

#### Is there a charge for the equipment?

No.

# What if I need different equipment or it needs to be repaired or I don't need it any more?

Contact your Support Coordinator, the health plan, or the supplier of the equipment.

# Where can I find additional information about durable medical equipment?

Additional information about durable medical equipment may be found in Chapter 600 of the Policy and Procedures Manual. The manual can be read at a local Division office or through the DDD website. You may also contact the health plan or physician.

#### What are Adaptive Aids?

Adaptive Aids may include:

- Traction equipment;
- Feeding aids (including trays for wheelchairs);
- Helmets;
- Standers, prone and upright;
- Toileting aids;
- Wedges for positioning;
- Transfer aids;
- Augmentative communication devices;
- Medically necessary car seats; or
- Other items determined medically necessary by joint consultation of the Medical Director of your health plan and the Division's Medical Director.

## How do I get them?

Typically, your Primary Care Physician or a doctor at Children's Rehabilitation Services will identify the need for the aid(s) and make arrangements for you to obtain the needed equipment.

#### Who provides them?

The health plan or the Division may provide the aids or you may purchase them.

#### Do I need an evaluation?

Your physician will determine if adaptive aids are needed.

# What are augmentative communication devices?

These devices enhance a person's ability to express wants and needs. Devices may range from simple picture boards to computerized devices.

#### Who is eligible for a device?

People must be Long Term Care eligible and must be making unsuccessful efforts to communicate. The Individual Support Plan team will identify the need for a device and the Support Coordinator will make the arrangements to obtain an appropriate device.

### Who provides them?

These devices are provided by the Division which sometimes works with local schools to share costs.

# Who owns the augmentative communication device?

If the Division purchases the device, the Division owns the device and you must return it once no longer needed (or make arrangements with your Support Coordinator for its return). If your health plan purchases the device, check with them to see who owns it.

# Where can I get more information?

Additional information about augmentative communication devices may be found in Chapter 600 of the Policy and Procedures Manual. The manual can be read at a local Division office or through the DDD website.

# What is Assistive Technology?

Assistive Technology devices are defined as any item or piece of equipment that is used to maintain, or improve the functional capabilities of a person with a disability.

Low-tech examples include pencil grips, adapted spoons, adapted handles, etc. High-tech examples include computers, augmentative communication devices, etc.

Assistive Technology Services include any service that directly assists a person with a disability in the selection, acquisition, or use of an assistive technology device. Examples are wheelchair evaluations, or training parents and family members in the use of devices, and repairs, etc.

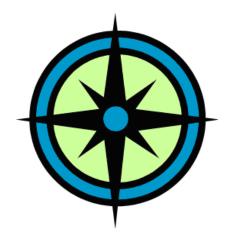
#### Who do I contact for more information?

Contact your Support Coordinator, or learn more about Assistive Technology by contacting:

Institute for Human Development Northern Arizona University Arizona Technology Access Program 4105 N. 20th Street, Suite 260 Phoenix, AZ 85016 602.728.9534 800.477.9921 http://www.nau.edu/ihd/aztap/

#### What is Children's Rehabilitative Services?

Children's Rehabilitative Services, a program of the Department of Health Services, provides medical treatment, rehabilitation and related support services to medically and financially qualified children and youth who have certain medical, disabling or potentially disabling conditions that have the potential for functional improvement.



# Who is eligible?

To be eligible for services through Children's Rehabilitative Services, a person must:

- Be an Arizona resident under 21 years of age; and
- Have a physical disability, chronic illness or a condition that is potentially disabling.

Conditions accepted for care include, but are not limited to:

- Conditions present at birth or acquired, such as club feet, dislocated hip, cleft palate, malunited fractures, scoliosis, spina bifida, and congenital genitourinary and gastrointestinal anomalies;
- Many muscles and nerve disorders;
- Some conditions of epilepsy; and
- Certain heart conditions.

#### What are the residency requirements?

The applicant must be, and intend to remain, in Arizona. Verification of residency consists of a signed affidavit stating the individual's intent to remain in Arizona and a rent receipt or vehicle registration showing where the individual lives.

# What services are provided?

Physician services, medications and outpatient services are a few examples of the services provided. Contact Children's Rehabilitative Services at one of the numbers noted below or visit the website <a href="http://www.azdhs.gov/phs/ocshcn/crs/crs\_az.htm">http://www.azdhs.gov/phs/ocshcn/crs/crs\_az.htm</a> for more information.

#### Is there a charge for services?

Families above 200% of the Federal poverty level are responsible for 100% of costs, based on the Medicaid fee schedule. Families below 200% of the Federal poverty level will not be billed.

# My child is Long Term Care eligible. Why do we have to use Children's Rehabilitative Services?

It is a Medicaid Long Term Care requirement.

# How does my child's Primary Care Physician fit into Children's Rehabilitative Services?

Children's Rehabilitative Services staff will work with your child's Primary Care Physician to exchange information and coordinate care.

#### Who provides the services?

Services are provided through four contracted provider hospital special/multidisciplinary clinics throughout the state and outreach clinics in 27 communities of the state. The hospital clinics are located in Phoenix, Tucson, Flagstaff and Yuma.

# Where are the special/multidisciplinary and outreach clinics located?

Phoenix	Tucson
Children's Health Center	Children's Clinic
124 W. Thomas Rd	2600 N. Wyatt Dr
Phoenix, AZ 85013	Tucson, AZ 85712
602.406.6400	520.324.5437
800.392.2222	800.231.8261

Flagstaff
Children's Rehab. Services
1200 N. Beaver
Floorate# A7 00001

Flagstaff, AZ 86001 928.773.2054 800.232.1018 Yuma

Children's Rehab. Services 2400 Avenue A Yuma, AZ 85364 928.344.7095 (collect calls accepted)

You may also access the locations through the website: http://www.azdhs.gov/phs/ocshcn/crs/crs\_az.htm.

# What if I am unhappy with a Children's Rehabilitative Services decision?

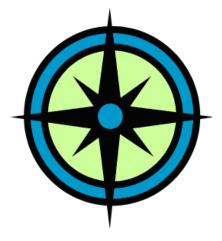
Children's Rehabilitative Services encourages parents to contact the patient advocate at the clinic if there is dissatisfaction with any of the services. Most problems can be resolved by talking with the patient advocate and the staff.

If there are issues concerning financial eligibility during the process at the clinic, these can often be resolved by working closely with the eligibility interviewer. If the issues cannot be resolved, the patient advocate at the clinic can provide information to the parent about the grievance process of the Arizona Department of Health Services.

# How can a parent impact Children's Rehabilitative Services?

The Parent Advisory Council is a statewide council that advises the Arizona Department of Health Services, Children's Rehabilitative Services clinics and physicians, regarding delivery of Children's Rehabilitative Services in the state. Council participation is open to all parents and interested professionals.

Contact the patient advocate in Phoenix at 602.406.6460, the patient advocate in Tucson at 520.324.3026, the social worker in Flagstaff at 928.773.2054 or the social worker in Yuma at 928.344.7294 for more information.



# **BEHAVIORAL HEALTH**

#### Who is eligible for behavioral health services?

People who are Title XIX or Title XXI eligible and have certain behavioral health conditions that can benefit from medically necessary behavioral health services are eligible. A person who is not Title XIX or Title XXI eligible and has been identified as having a serious mental illness may be eligible.

# Who can make a referral and what happens after a referral is made?

Almost anyone can make a referral. You may refer yourself. A family member, your doctor or Support Coordinator may also make the referral. An appointment for an intake interview will be made within seven (7) days of the referral. If you are found eligible for services, an appointment will be made within 30 days to begin planning and treatment.

#### What services are available?

Services fall into three (3) categories: Prevention, Evaluation and Treatment. Prevention services provides information, attitude and skills to help you lead a healthy life. Evaluations help determine what your issues may be and what to do about them. Treatment may include counseling, crisis response, medications, in-home supports, etc.

#### Is there a charge for services?

There is no charge for services if an individual is Title XIX or Title XXI eligible or eligible for the "serious mental illness" program.

# What if I am not happy with the decision regarding my eligibility or my treatment plan?

You may file a service appeal. Contact your Support Coordinator for assistance.

#### What is the role of the Support Coordinator relative to behavioral health services?

A general definition of a Support Coordinator is found in the "Overview" section of this guidebook. For behavioral health services a Support Coordinator can also assist with the referral process. A Support Coordinator is also responsible for being an advocate, coordinating care, and exchanging information with key individuals in the behavioral health system.

#### Who can I contact for more information?

Your Support Coordinator can provide additional information or contact the Department of Health Services/Behavioral Health Services at 602.364.4558 or through the website at <a href="http://www.azdhs.gov/bhs/index.htm">http://www.azdhs.gov/bhs/index.htm</a>.

# **SAFEGUARDS**

The health and safety of a person with developmental disabilities is always an important consideration for everyone involved in that person's life. The Division has many systems in place to help ensure that the rights of people with developmental disabilities are upheld and that health and safety are maintained. This section of "Navigating the System" provides information about safeguards and systems that are available to resolve concerns, obtain information or advocate for change.

#### **ADVOCACY**

#### What is it?

Advocacy is active support for a cause or position. Parents and self-advocates know what it means...to strive to obtain what is right for an individual.

#### Who do I contact?

There are many advocacy and support organizations in Arizona. The Division of Developmental Disabilities, Office of Consumer and Family Support, has advocates on staff. An advocate may be reached at 602.542.0419 or 866.229.5553 or by email at dddweb@azdes.gov Below is a complete listing of other agencies that provide advocacy. Remember: alone, every individual is a very powerful advocate. No one else can have the same passion.

The Arc of Arizona	602.234.2721

866.501.2721

http://arcarizona.org

Arizona Bridge to Independent Living 602.256.2245

800.280.2245 http://abil.org

Arizona Center for Disability Law 602.274.6287

800.927.2260

http://www.azdisabilitylaw.org

Arizona Consortium for Children with Chronic Illness 480.557.8445

Autism Society 480.940.1093

http://www.phxautism.org

Epilepsy Foundation of Arizona 602.406.3851

888.768.2690

www.epilepsyfoundation.org/

arizona/

Governor's Council on Developmental Disabilities 602.277.4004

800.889.5893

http://www.azgcdd.org/

Pilot Parents of Southern Arizona 520.324.3150

877.365.7220

http://pilotparents.org

People First of Arizona 602.522.0495

http://www.cpes.com/

advocacyresources/selfadvocacy/

peoplefirst.htm

Raising Special Kids 602.242.4366

800.237.3007

http://raisingspecialkids.org

#### Is there a charge?

Most advocacy agencies are free of charge. Some accept donations or charge a fee.

#### ARIZONA CENTER FOR DISABILITY LAW

# Who are they?

The Arizona Center for Disability Law is a not-for-profit public interest law firm dedicated to protecting the rights of people with a wide range of physical, psychiatric, sensory and cognitive disabilities.

#### What do they do?

As part of the nationwide protection and advocacy system, the Center provides training and free legal services under several major incentives:

- Protection and Advocacy for Individuals with Mental Illness;
- Protection and Advocacy for Individuals with Developmental Disabilities;
- Client Assistance Program;
- Assistive Technology Access Program;
- Housing and Urban Development/Fair Housing Initiatives Program; and
- Protection and Advocacy of Individual Rights.

#### Is there a charge?

No.

#### How can I contact them?

3839 N. 3<sup>rd</sup> Street, Suite 209 Phoenix, AZ 85012 602.274.6287 800.927.2260

http://www.azdisabilitylaw.org

100 N. Stone Avenue, Suite 305 Tucson, AZ 85701 520.327.9547 800.922.1447

#### DEVELOPMENTAL DISABILITIES ADVISORY COUNCIL

#### What is it?

The Developmental Disabilities Advisory Council is a twelve member group of volunteers appointed by the Governor. Council membership includes people with developmental disabilities, family members, advocates, providers and representatives from state agencies.

# What do they do?

The Council reviews and makes recommendations to the Division of Developmental Disabilities regarding:

- Coordinating and integrating services provided by state agencies and providers that have contracted with state agencies to provide supports to people with developmental disabilities;
- Health, safety, welfare and legal rights of individuals with developmental disabilities:
- Establishing and reviewing Division policies and programs;
- Annual rate setting methodology;
- Assessing the Division's annual needs:
- Selecting the Assistant Director of the Division; and
- Monitoring the Division's annual budget.

The Council also oversees and approves expenditure of monies from the Client Services Trust Fund which was established after the sale of the former Arizona Training Program at Phoenix.

#### Who do I contact?

For information about the Developmental Disabilities Advisory Council, call 602.542.0419 or 866.229.5553 or visit the website http://wwww.azdes.gov/ddd/faqs/faq\_dddac.asp.

#### **HUMAN RIGHTS COMMITTEES**

# What are the Human Rights Committees?

The Human Rights Committees are groups of local citizens who provide independent oversight in matters related to the rights of people with developmental disabilities who are supported by the Arizona Department of Economic Security/Division of Developmental Disabilities.

# What do Human Rights Committees do?

Committees usually meet once a month to:

- Review any incidents that may have involved neglect, abuse or denial of rights of people receiving supports;
- Review programs which might infringe on the rights of people receiving supports,
   e.g., programs which involve the use of behavior modifying medications;
- Review any proposed research involving people receiving supports;
- Make recommendations to the Division of Developmental Disabilities about changes needed to protect the rights of people receiving supports.

#### Who serves on the Human Rights Committees?

Members are volunteers. They may include people who receive supports and their families, advocates, psychologists, physicians, nurses, attorneys, clergy, pharmacists, social workers, teachers, business people and any other community members who are committed to the rights of all people. Members are recommended by local Human Rights Committees and appointed by the Director of the Department of Economic Security.

# What experience or training do Human Rights Committee members need?

A sincere interest in the rights of all Arizona residents is the key requirement. Training is provided to prepare new members and all members receive ongoing training to keep them up to date on important issues.

# Who can raise an issue to the Human Rights Committees?

Issues can be raised by anyone who has a concern about a possible violation of the rights of a person with developmental disabilities who is eligible for services from the Division of Developmental Disabilities. Contact one of the offices and ask for the name of the Human Rights Committee Chairperson. Concerns will be handled in a confidential manner in accordance with state laws and regulations.

# What kind of issues should be raised to one of the Human Rights Committees?

Any suspected violations of rights of a person with developmental disabilities such as mistreatment or discrimination. If the Human Rights Committee is not the best group to handle the concern, you will be referred to the appropriate agency.

#### What are some of the challenges the Human Rights Committees have addressed?

In addition to dealing with a wide variety of individual issues, Human Rights Committees have been involved with many policy issues that relate to rights. These issues have ranged from matters of health and safety to personal power and choice. The committees make recommendations for action and raise awareness of the rights of people with developmental disabilities. The task of the committees is critical if the rights of all Arizona citizens are to be respected.

#### How do I get involved or get more information?

Contact your District Program Manager/Administrator or go to http://www.azdes.gov/ddd/faqs/faq\_hrc.asp.

#### **INCIDENTS**

# What are they?

An **Incident** is an occurrence that could potentially impact the health and well being of a person receiving Division funded services or to the community. The Division defines two categories of incidents: incidents and serious incidents. When an incident occurs, the Division is required to take some type of action.

An **Incident** includes things like an occurrence of inappropriate sexual behavior; theft or loss of the eligible person's money (less than \$25.00); a medication error where the person was given the wrong medication or circumstances which pose a threat to health, safety or welfare of eligible people such as loss of air conditioning, loss of water or loss of electricity for more than one day.

A **Serious Incident** is a serious and extraordinary event involving an eligible person, facility, or employed/contracted personnel. A serious incident poses the threat of immediate death or severe injury to a person, substantial damage to individual or State property, and/or widespread interest in the news media.

# Who can report an incident?

Anyone who witnesses an incident may report it by calling the Support Coordinator.

#### Will I be notified of the incident?

The responsible person will be notified unless otherwise specified in the Individual Support Plan. The procedures for notification of the responsible person should be coordinated between the service provider and the Support Coordinator. The Support Coordinator or designated District staff member should ensure notification of the responsible person of a serious incident within 24 hours of its occurrence. The responsible person may choose not to receive notification of incidents.

#### What is an investigation?

An investigation is a review of the incident for the purposes of describing and explaining the incident. The investigation may involve a review of the provider's incident reports, as well as a review of other records maintained in the provision of services. An investigation will typically include interviewing of the individual reporting the incident, the service provider and/or clients who might have additional information or insight regarding the incident.

#### Who does it?

Division staff with special qualifications will investigate the incident. Law enforcement, Adult Protective Services or Child Protective Services may also investigate it.

# Can I have a copy of the results?

Investigative reports incidental to or resulting from an incident Report are considered confidential and are maintained at the District Office. The Assistant Director/designee may send the results of investigations conducted by the Division to providers. The individual/responsible person, upon written request, may receive the results. Human Rights committees will receive the results of investigations.

#### Where can I get more information?

Additional information may be found in Chapter 2100 of the Policy and Procedures Manual. You can go to your local Division Office to read the manual or find it on the web at https://www.azdes.gov/ddd/reference/policyproc.asp.

# LAWS, RULES, POLICIES AND PROCEDURES

## What are they?

Laws are passed by the Legislature (see Legislative Process). Laws define, in broad terms, what will happen. State Agencies then develop Rules which clarify laws into an understandable form. From Rules, Policies and Procedures are developed which state how a state agency will implement the laws and rules and provide guidance to staff, providers and people with developmental disabilities and their families.

#### Where can I find them?

If you know the number of the law, you may find it on-line at <a href="http://www.azleg.state.az.us/">http://www.azleg.state.az.us/</a>. If you don't the number, you may search that site for key words. Local libraries also have copies of Arizona laws.

Rules are available from the Secretary of State by calling 800.458.5842 or at <a href="http://www.azsos.gov/">http://www.azsos.gov/</a>.

Policies and Procedures are available at all local Division Offices or at http://www.azdes.gov/ddd/reference/policyroc.asp.

# How do they apply to me?

All laws, rules, policies and procedures affect what happens to a person who is eligible for services through the Division. Public comment is an option in the development of laws, rules and policies and procedures.

#### Who do I contact with questions?

Call the Division at 602.542.0419 or 866.229.5553 or email dddweb@azdes.gov.

#### **ISSUE RESOLUTION**

#### What is it?

There may come a time in your relationship with the Division and its staff and providers that communication breaks down or you feel needs are not being met.

Typically, your Support Coordinator will be the person best able to respond to issues, problems or concerns. You are encouraged to discuss any issues with them.

If your Support Coordinator is not able to take care of your concern, you may want to contact his/her supervisor to assist you. There are also others who may assist you including your District Program Manager or Administrator. For a list of District Program Managers/ Administrators and telephone numbers, please see the Office Listing. The Division's Office of Consumer and Family Support has advocates available to assist you if you still encounter problems. The staff of this office are experienced in resolving conflicts and are available to you by calling 602.542.0419 or 866.229.5553 or at dddweb@azdes.gov.

If you have a concern with your health plan, attempt resolve the issue with your physician or with the Member Services representative.

#### What if my issue or concern is still not taken care of?

Most issues and concerns can be resolved using the methods described above, however, there are other options available to you.

You may wish to file an appeal directly to AHCCCS (if you are eligible for Long Term Care). Staff of the Division's Office of Compliance and Review will investigate your issue, research applicable laws, rules and procedures and make a recommendation to the Assistant Director of the Division. The Assistant Director, or designee, will make a final, written decision regarding your concern. If you disagree with that decision, you may appeal it. You will be given information about next steps when you receive your written decision.

# Were can I get additional information?

Additional information about Issue Resolution may be found in Chapter 2200 of the Policy and Procedures Manual. You can go to your <u>local Division</u> office to read the Manual or at <a href="http://www.azdes.gov/ddd/reference/policyproc.asp">http://www.azdes.gov/ddd/reference/policyproc.asp</a>.

#### ACCESS TO RECORDS

#### Who can see records?

You may review your records. Staff of other state agencies may also see your records, as appropriate.

#### When can I see them?

Typically, you may see your records at any time, however, in some situations, this may not be possible.

#### May I have copies and is there a charge for them?

You may have copies. Typically, you may see the records within 30 calendar days of your request. You will not be charged.

#### Who do I contact?

Contact your Support Coordinator.

#### Where can I find more information?

Additional information about records may be found in Chapters 1500 and 1800 of the Policy and Procedures Manual. You can go to you local Division office to read the Manual or at <a href="http://www.azdes.gov/ddd/reference/policyproc.asp">http://www.azdes.gov/ddd/reference/policyproc.asp</a>.

#### HOME AND COMMUNITY BASED CERTIFICATION

#### What is it?

Home and Community Based Certification is a credentialing process that ensures individual and agency providers meet certain basic requirements such as training in First Aid and Cardiopulmonary Resuscitation. Reference checks and fingerprint clearances are important components of certification.

#### Why are providers certified?

Providers are required to be certified in accordance with state and Federal requirements.

#### What is the process and what are the requirements?

The requirements vary according to the service to be provided. A complete description of the process and requirements can be found at <a href="http://www.azdes.gov/ddd/reference/rules.asp">http://www.azdes.gov/ddd/reference/rules.asp</a> in Article 15 or you can get them at your local office.

#### Can requirements be waived?

Requirements may not be waived, however, requirements for certain family members are not as stringent.

#### **TRAINING**

#### What is available?

Many different trainings are available and are provided by a variety of sources. For training provided by the Division, contact your Support Coordinator. Other trainings are offered and you can find out about them at <a href="http://www.ade.az.gov/ess/eapn/Default/asp">http://www.ade.az.gov/ess/eapn/Default/asp</a>.

#### Is there a charge for this?

Most training is free of charge.

#### Who do I contact?

Contact information about training can be found at <a href="http://www.ade.az.gov/ess/eapn/Default/asp">http://www.ade.az.gov/ess/eapn/Default/asp</a>.

# **BITS AND PIECES**

How do you categorize bits and pieces of information that do not fit in other sections of a guidebook? You put in a section titled Bits and Pieces! This section of "Navigating the System" will provide you with information on the Governor's Council on Developmental Disabilities, the University Centers on Disabilities, other services offered through the Department of Economic Security and the Legislative process.

#### GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES

#### What is it?

The mission of the Governor's Council on Developmental Disabilities is to bring together people with disabilities representing Arizona's cultural diversity and their families and other community members, to protect rights, eliminate barriers, and jointly promote equal opportunities. This is achieved through statewide planning, advocacy, monitoring and community action for public policy change.

#### What do they do?

The Governor's Council on Developmental Disabilities works for the benefit of individuals with disabilities, their families, friends and employers as well as businesses, law enforcement agencies, legislators, schools...in fact all Arizonans. The Governor's Council on Developmental Disabilities works to build bridges, increase understanding and create opportunities to banish misconceptions and change public policy. The Governor's Council on Developmental Disabilities believes that individuals with developmental disabilities should have every opportunity to achieve their maximum potential to be independent, productive and integrated into the community of their choice.

#### Who do I contact?

If you can help in any way, or if you need help, please call the Governor's Council on Developmental Disabilities at 800.889.5893 or 602.277.4004, TTY 602.277.4949 or http://www.azgcdd.org.

#### **UNIVERSITY CENTERS ON DISABILITIES**

# Who are they?

The Arizona University Centers on Disabilities are programs established through Federal law entitled, "Developmental Disabilities Assistance and Bill of Rights Act of 2000" (Public Law 106-402). It is one component of a national program that include the Councils on Developmental Disabilities and Protection and Advocacy systems. The goal of University Centers is to bring the resources of universities to communities across the state to improve the lives of people with developmental disabilities and their families.

The Arizona University Centers on Disabilities are part of a national network of University Centers based in every state and territory where a university can be found.

# What do they do?

The Arizona University Centers on Disabilites conduct university-based training for-credit and non-credit for future and current professional who work or who plan to work with persons with developmental disabilities and their families. These activities include courses and programs of studies that lead to a Certificate in Disability Studies.

The Arizona University Centers on Disabilities also provides a host of community-based trainings for continuing education and professional development. It also conducts research and evaluation to expand the knowledge in the field of disabilities. The Arizona University Centers on Disabilities publishes and disseminates the results of its activities through various means including text, electronic and video formats

#### Is there a charge?

No.

#### How can I contact them?

Northern Arizona University
Institute for Human Development
Arizona University Center on Disabilities
PO Box 5630
Flagstaff, Arizona 86011-5630
928.523.4791
928.523.4791
928.523.1695 TDD
http://www.nau.edu/ihd/

Sonoran UCEDD 1521 E. Helen Street Tucson, Arizona 85719 520.626.0080 http://sonoranucedd.fcm. arizona.edu/contactus.cfm

#### SERVICES WITHIN THE DEPARTMENT OF ECONOMIC SECURITY

The Division of Benefits and Medical Eligibility provides, under the Family Assistance Administration, financial assistance and/or food stamps to eligible applicants and recipients. It also determines eligibility to receive medical benefits from the Arizona Health Care Cost Containment System and provides, under the Disability Determination Services Security Insurance programs. For additional information call 602.542.3596 or at <a href="http://www.azdes.gov.faa/">http://www.azdes.gov.faa/</a>.

The Division of Children, Youth and Families is dedicated to achieving safety, well-being and permanency for children, youth and families. Programs under this Division include Healthy Families Arizona, Family Builders Program, Family Advocacy Office, Child Protective Services, Adoption Services, and the Comprehensive Medical and Dental Program for foster children. For additional information, call 602.542.3598 or http://www.azdes.gov/dcyf.

The Division of Child Support Enforcement provides the following services: finding the parent or alleged parent, creating a legal relationship between the absentee parent and child, obtaining a legal child support obligation, changing an existing legal child support order and collecting child support payments. Currently in Arizona, there is no application fee of any kind. For more information call 602.274.7646 or at <a href="http://www.azdes.gov/dcse">http://www.azdes.gov/dcse</a>.

The Division of Aging and Community Services is responsible for administering a statewide comprehensive system of programs and services for aging and vulnerable adults. Programs include Foster Grandparent Program, Adult Protective Services, Domestic Violence Program, Low-Income Home Energy Assistance Program, Refugee Resettlement, Telephone Assistance Program and the Senior Telephone Discount Program. For more information call 602.542.6572 or at <a href="http://www.azdes.gov/aaa">http://www.azdes.gov/aaa</a>.

The Division of Employment and Rehabilitation Services provides numerous services under various administrations including:

- Child Care Administration which provides assistance with child care costs for eligible Families;
- Employment Security Administration which provides services to employers and individuals seeking new jobs, better jobs or first jobs;
- Jobs Administration which provides help to public assistance recipients to obtain employment that will lead to economic independence;
- Rehabilitation Services Administration which provides a variety of specialized services to individuals with physical or mental disabilities that create barriers to employment or independent living.

Call 602.542.4910 for addition information.

**The Division of Employee Services and Support**, through the Office of Licensing, Certification and Regulation, is responsible for issuing developmental home licenses, certifies home and community based service providers. It also does life safety inspections of all facilities certified to provide "out of home" services. This unit is responsible for completing criminal record checks for providers and Division of Developmental Disabilities staff. For more information, call 602.347.6340.

#### LEGISLATIVE PROCESS

# Why would I care about the legislative process?

**You** can make a difference. Having a voice in our government is the responsibility of all of us. Listening to our voices is the responsibility of our legislators.

#### How is legislation enacted in Arizona?

The process of enacting legislation is a complicated undertaking from the time a bill is drafted until it is finally passed and sent to the Governor. Legislation may be suggested by anyone - legislators, state agencies, advocacy organizations, legislative committees, lawyers, constituents (you), and others for presentation to a Senator or Representative for introduction in the Senate or House.

#### How can I influence the process or have my voice heard?

You may write or call your legislator. You may also provide public testimony at hearings. Remember that your ideas are important.

#### Who can I contact for more information?

Partners in Policy making is a course for people with disabilities and their families to help learn more about public policy and how to influence its development. Contact Pilot Parents of Southern Arizona at <a href="http://www.pilotparents.org/pilot\_pip.htm">http://www.pilotparents.org/pilot\_pip.htm</a> or at 520.324.3150 or 877.365.7220. Current and historical information about bills, as well as a detailed description of the legislative process is available at the Arizona Legislative Information System at <a href="http://www.azleg.state.az.us">http://www.azleg.state.az.us</a>.

#### **DIVISION WEB SITE**

#### Where is it?

The Division's web site is at http://www.azdes.gov/ddd.

#### What is on it?

The site includes general information about the Division at "Working with You". It has a reference section that has all applicable laws, policies and procedures. Acronyms are explained and there are links to other sites. It also has an area for newsletters and items of current interest. "About DDD" provides the Division's Mission and Values. There is an area containing contact information as well as "Frequently Asked Questions" about developmental homes, the Client Services Trust Fund, the Developmental Disabilities Advisory Council and Human Rights Committees.

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# Arizona Department of Economic Security Division of Developmental Disabilities



Equal Opportunity Employer/Program - Under Titles VI and VII of the Civil Rights Act of 1964 (Title VI & VII), and the Americans with Disability Act of 1990 (ADA), Section 504 of the Rehabilitation Act of 1973, and the Age Discrimination Act of 1975, the Department prohibits discrimination in admissions, programs, services, activities, or employment based on race, color, religion, sex, national origin, age, and disability. The Department must make a reasonable accommodation to allow a individual with a disability to take part in a program, service or activity. For example, this means if necessary, the Department must provide sign language interpreters for people who are deaf, a wheelchair accessible location, or enlarged print materials. It also means that the Department will take any other reasonable action that allows you to take part in and understand a program or activity, including making reasonable changes to an activity. If you believe that you will not be able to understand or take part in a program of activity because of your disability, please let us know of your disability needs in advance if at all possible. To request this document in alternative format or for further information about this policy, contact the Division of Developmental Disabilities ADA Coordinator at (602) 542-6825; TTY/TDD Services: 7-1-1.

